Attention please!

Munde, Vera Solveig

1 Introduction

Providing support and education for individuals with profound intellectual and multiple disabilities (PIMD) is a challenging task for direct support persons (DSPs). One of the barriers that DSPs experience is timing. Individuals with PIMD only show short periods of *being focused on the environment* or *being alert* (Guess, Roberts, & Guy, 1999). Moreover, these short moments are often difficult to detect because of individual differences in how alertness is expressed (Mudford, Hogg, & Roberts, 1997). Based on these difficulties, DSPs face recurring questions when they approach individuals in the target group: What is the best moment to start an activity or an interaction? How can we determine the *best moment* or being alert? What is the duration of such a moment? And how can we provoke these moments so that they occur more frequently?

While researchers and DSPs agree upon the importance of alertness in the support and education of individuals with PIMD, they face three main problems that are related to the topic. First, unambiguous terminology and descriptions of these terms are lacking for the target group. In previous studies, different terms have been used to designate the moments of being focused on the environment. Moreover, the descriptions differ for different terms, and even different descriptions for the same term can be found (Foreman, Arthur-Kelly, Pascoe, & King, 2004; Green, Gardner, Canipe, & Reid, 1994; Guess et al., 1993; Mellstrom, Saunders, Saunders, & Olswang, 2005). At the same time, an unambiguous description of alertness is necessary as a basis for all further research and knowledge.

Second, researchers and DSPs wonder how best to determine alertness. While it is difficult to detect the short alert periods of individuals with PIMD, the quick and irregular changes between being alert and not being focused on the environment aggravate this task still more (Guess et al., 1999; Mudford et al., 1997). In addition, an assessment method is needed that is capable of taking individual differences in alertness expressions into

account. While observation yields this possibility, DSPs are then obliged to interpret the alertness expressions noted in their observations. Because of this, the subjective component of the interpretation becomes a threat to the reliability of this method (Hogg, Reeves, Roberts, & Mudford, 2001). Alternative assessment methods such as brain measurements and physiological measurements exist, but they are also difficult to implement when it comes to individuals of the target group (Kemner, Van der Gaag, Verbaten, & Van Engeland, 1999). Because measurements can be biased by the disabilities of the individual, interpretation of the results may not be the same as that for a nonclinical population. Based on these issues, the discussion about assessment methods for alertness in individuals with PIMD is an ongoing one.

Finally, only a small number of studies have been conducted to ascertain the possibilities for influencing alertness in individuals with PIMD and, therefore, reaching the alertness levels that are optimal for learning and development. Previous studies often included only a small number of participants, and the research methods used were not always comparable to each other (e.g., Cuvo, May, & Post, 2001; Lindsay, Pitcaithly, Geelen, & Buntin, 1997). Because even similar studies have come up with different results, empirical studies concerning those factors that may have an impact on alertness are badly needed.

1.1 The target group: individuals with PIMD*

A profound intellectual disability is almost always the consequence of neurological impairments arising from trauma or genetic influences (Arvio &

* This section is based on the following article: Munde, V.S. & Vlaskamp, C. (2010). Alertness observations in children with profound intellectual and multiple disabilities. *International Journal of Child Health and Human Development*, *3*(1), 115-124.

Sillanpää, 2003). The implications apply to almost all aspects of the person's functioning. Central nervous system (CNS) damage results in profound intellectual disorders, severe or profound motor disorders (e.g., spastic quadriplegia), and sensory disorders. Characteristically, individuals with PIMD function at the preverbal stage of communication. Only some of them have spoken or signed expressive language and their communicative comprehension is at a low level. Their understanding of causality and space is always limited. Because of the minimal level of their adaptive and self-help abilities, individuals of the target group require pervasive support. Another consequence of such CNS damage is that most individuals with PIMD are wheelchair users. In addition, they have difficulties in maintaining postural balance and the use of hands and arms is very limited. Both gross motor and fine motor functions are profoundly disturbed. Furthermore, sensory impairments are also common. Recent studies show that at least 85% of people with profound intellectual disabilities experience visual impairment (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). In most cases this is caused by damage to the visual cortex in the occipital lobe (cortical blindness). Between 25% and 33% of individuals with profound intellectual disabilities suffer from auditory impairment, but it is suspected that a substantial number of such cases may actually remain unidentified (Evenhuis, Mul, Lemaire, & De Wijs, 1997; Evenhuis et al., 2001). In addition, dysfunctions of taste and smell are also relatively common (Doty et al., 2002). The tactile and coetaneous senses that include the receptors of touch, pressure, temperature, and pain are frequently thought to be impaired to some degree as well (Dunn, 1999; Oberlander, Gilbert, Chambers, O'Donnell, & Craig, 1999). However, assessment of these dysfunctions is difficult and, therefore, they are rarely taken into account. In addition to the intellectual, motor, and sensory disabilities just noted, further concomitant impair-

ments should also be mentioned as they, too, have significant implications for daily functioning. Extensive additional impairments include: seizure disorders, chronic pulmonary infections, and skeletal deformations (Evenhuis et al., 2001; Hogg, 1992; Janicki & Dalton, 1998; Van Schrojenstein Lantman-de Valk, Van den Akker, Maaskant, & Haveman, 1997; Van Splunder et al., 2006).

Since each individual represents a unique configuration of abilities and constraints in regard to functioning, individuals with PIMD form a heterogeneous group in terms of central nervous system integrity, physical growth, development, and behavioral repertoires (Zijlstra & Vlaskamp, 2005). Notwithstanding this huge diversity, individuals with PIMD are comparable in terms of the degree of their profound intellectual disabilities, along with their severe or profound motor disabilities. They form a very vulnerable group with heavy or total dependence on personal assistance for their physical care, education, stimulation, and recreation.

1.2 Aim of the research

The present thesis aims to reach a better understanding of alertness in individuals with PIMD. To this end, the focus is threefold. An unambiguous description of alertness needs to be formulated first, but providing a reliable and valid instrument for DSPs to determine alertness has to be the second step. Based on this, an empirical study should then be able to show which environmental factors may have an impact on alertness in individuals in the target group.

Because the first two aims have a conditional relationship with the third aim, the main research question of the present study is the following:

How can we influence alertness in individuals with PIMD?

To answer this main question, three sub-questions have been formulated.

How can we describe alertness?

How can we determine alertness?

How can we influence alertness?

1.3 Outline of the thesis

The present thesis consists of three parts. First, a review of the literature will summarize previous research and highlight the remaining problems in describing, determining, and influencing alertness. Because this study still left several questions open, a group of experts was asked to discuss the results. This Concept Mapping procedure revealed additional information that could be used to clarify the problems.

In the second part, the Alertness Observation List (AOL) will be presented. To provide an instrument with good psychometric qualities for DSPs, the reliability of the AOL was investigated, calculating the inter-observer and intra-observer agreement for a sample of observations. Subsequently, the validity of the instrument was then able to be described based on a comparison of observations with physiological measurements.

Third, two analyses of an empirical study will be described. By considering stimulation situations in a multisensory environment as a potential activity for influencing alertness levels in individuals with PIMD, the first analysis will focus on the impact of different aspects of a stimulation situation on the various alertness levels. Based on this analysis, we will then look at the sequential effects of alertness and the different stimuli in the stimulation situation.

In the concluding chapter, the results of all the studies will be linked back to the research questions. Limitations, implications for clinical practice, and suggestions for future research will be discussed.

The outline of the thesis is visualized in Figure 1.1.

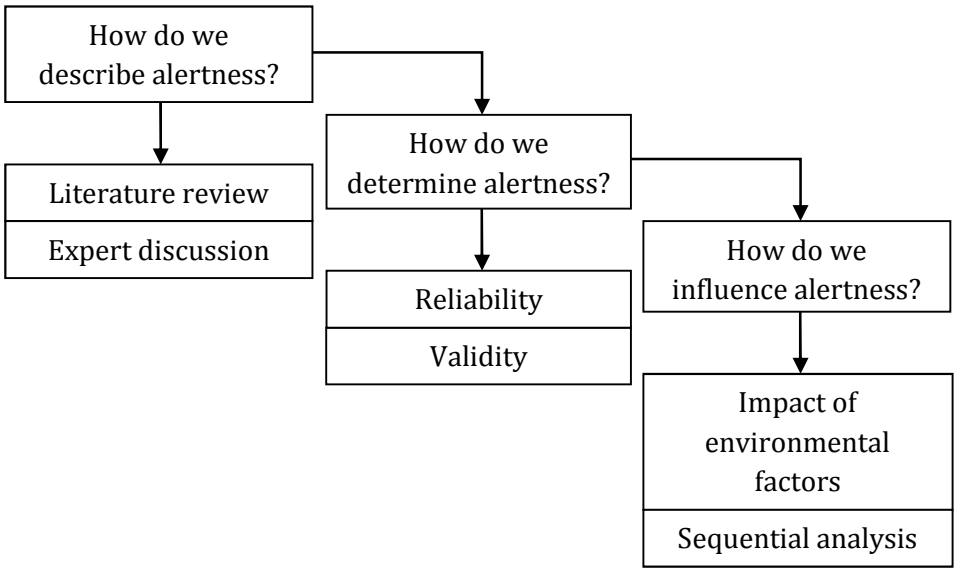

Figure 1.1 Outline of the thesis